Coping as a Moderator of the Associations between Risk Knowledge, Perceived Risk, and Health Behaviors in Adolescents and Young Adults with Congenital Heart Disease

Research Thesis

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by

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Abstract

There is a growing population of individuals with congenital heart disease (CHD) who now survive into adulthood. These individuals are at risk for future cardiac related comorbidities and research shows they have a poor understanding of healthcare requirements necessary to mitigate them. Patient perception of future health risks has not been explored in CHD patients and may influence how well individuals deal with future complications. This study evaluated future risk perception by measuring perceived risk, which is the number of future health complications a patient believes he/she is at risk and risk knowledge, which is how accurate an individual is based off of personal diagnosis. Furthermore, this study evaluated the association between perceived risk, risk knowledge and specific health behaviors related to diet and exercise that may improve health outcomes. The study also evaluated how this relationship is moderated by coping. Coping is voluntary behavior that involves engaging or disengaging with stressors. Participants included adolescents and adults with CHD (N=200) at Nationwide Children's Hospital ranging in age from 15-39 (M = 24.5 ±6.7) with varying levels of disease severity (simple = 23%, moderate= 45%, severe= 32%). Self-report measures included a CHD knowledge questionnaire evaluating perceived risk and risk knowledge, saturated fat intake and physical activity, and a response-to-stress questionnaire to identify coping styles. Results showed an association between perceived risk and risk knowledge (r = .58, p=.01). A positive correlation was found between age and risk knowledge (r= .49, p=.01). Multiple regression analysis showed that coping strategies did not interact with risk knowledge to predict saturated fat intake or physical activity.

Due to significant medical advancements in the diagnosis and treatment of congenital heart disease (CHD), there is a growing population of individuals with CHD who now survive into adulthood. Complex heart conditions that would have been fatal for children in the past are now identifiable and treatable early in life, allowing patients to survive childhood and go on to lead relatively normal adult lives. Currently there are more than 1,000,000 adults living with CHD in the United States and this number is expected to grow by 5% each year (Brickner, Hills, Lange, 2000). However, due to the nature of CHD and the likelihood for future health complications, many of these patients require regular appointments with a cardiologist throughout adulthood to manage their conditions (Warnes et al., 2008).

Guidelines from the American College of Cardiology and the American Heart Association (ACC/AHA) recommend that individuals with CHD assume increasing responsibility for their healthcare as they approach and enter adulthood (Warnes et al., 2008). This is often recommended in the form of attending regular follow-up care appointments with an adult cardiologist, but individuals can also assume responsibility for their healthcare by in engaging in positive health behaviors. This is because of the numerous health complications that CHD patients are at risk for later in life that may be prevented by certain health behaviors (Oechslin, Harrison, Connelly, Webb, Siu, 2000).

Recommended behaviors for someone with CHD that may off-set future health complications include eating a heart-healthy diet, specifically a diet low in saturated fat (Eckel et al., 2013) and engaging in at least some form of regular physical activity (Sable, Foster, Uzark, et al., 2011). Future health complications that may be mediated by these diet and exercise recommendations include hypertension, stroke, heart failure and

atherosclerosis (Sable et al., 2011). Furthermore, some risks are simply due to aging and so all CHD patients are at risk for some kind of future heart related complication.

Research suggests that adolescents and adults with CHD have a poor understanding of their condition and the specific healthcare requirements that are necessary to mitigate these future health complications. When adolescents with CHD are asked to identify the name of their diagnosis and explain what is wrong with their heart, less than one third are able to do so (Veldtman et al., 2000). Similar deficits are found in how well adult CHD patients understand their diagnosis (Iversen, Vejlstrup, Sondergaard, Nielsen, 2007).

Therefore, individual differences in CHD knowledge, understanding of recommended health behaviors, and perception of future health risks might influence adoption of healthy lifestyle choices. For example, Sable et al. (2011), found that barriers preventing individuals with CHD from engaging in regular physical activity include attitudes towards exercise, such as fear about the weakened state of their heart due to CHD and therefor thinking that exercise is unsafe (Sable, Foster, Uzark, et al., 2011). This finding demonstrates that a lack of knowledge in people with CHD about exercise could be compromising their ability to prevent future health complications.

It has been shown that only 15% of adolescents with CHD participate in the recommended amount of physical activity necessary to mitigate these complications (Massin, Hovels-Gurich, Seghaye, 2007). Furthermore, in the general population, activity levels generally decline from adolescence through young adulthood (Caspersen, Pereira, Curran, 2000). In terms of saturated fat intake, little is known about diets of adolescence and young adults with CHD. It is recommended that individuals consume less than 10%

of their daily calories from saturated fat in order to prevent heart related complications however, the general population of the United States exceeds this with 15% of daily calories coming from saturated fat (German & Dillard, 2004).

Surprisingly, there has been almost no research evaluating the relationship between illness knowledge and health behaviors for adolescents and young adults with CHD. More specifically, very little research has attempted to identify whether these individuals are aware of cardiac complications for which they are at risk in the future or the symptoms of these complications (Van Deyk, Pelgrims, Troost, et al., 2010). Furthermore, no published studies could be located that examine the association of health behaviors or others aspects of self-management with understanding of future cardiac risks.

Because individuals with CHD are at risk for future complications it is important that they know how to care for themselves in order to prevent the development of these complications. However, if individuals have limited illness knowledge, especially poor understanding of future risks, they may not engage in the necessary positive health behaviors. Poor illness knowledge in individuals with CHD, as well as poor management of chronic stress, may lead them to discontinue recommended treatment and routine follow-up care, putting them at even greater risk for future health complications due to their CHD (Brickner et al., 2000).

Individual understanding of illness has been found to correlate with improved mental quality of life (Veldtman et al., 2000). Although research exists that examines how quality of life varies in adults with CHD due to disease severity (Fteropoulli, Stygall, Cullen, Deanfield, Newman, 2013), until recently, how this relationship is affected by

illness knowledge could not be explored due to the lack of a measure of risk knowledge in CHD patients. With the development of the CHD Assessment of Information Measure (AIM) it has become possible to collect thorough data on illness knowledge, specifically future risk knowledge, in people with CHD. This allows for the examination of how illness knowledge influences both mental and physical quality of life.

In terms of mental quality of life, living with a chronic illness presents many acute and chronic sources of stress. According to the ACC/AHA guidelines, a barrier to accessing appropriate follow-up care in CHD patients is cognitive and psychosocial impairment, as well as insufficient management of the stresses of having CHD (Warnes et al., 2008). Despite this description by the ACC/AHA, stressors among individuals living with CHD have not been assessed and little is known about what elements of disease management are impacting engagement in positive health behaviors. These stressors may include treatment demands, uncertainty or concern about future health complications, and difficulties completing day-to-day tasks and activities. It has been found that persistent stress in individuals living with a chronic illness can contribute to emotional and behavioral problems, which can ultimately interfere with one's ability to comply with the demands of treatment (Compas, Jaser, Dunn, Rodriguez, 2012). In the case of people with CHD, this may include participating in preventative health behaviors.

Little information is known about how levels of health behaviors may be influenced by individual differences in how individuals appraise and cope with stressors associated with CHD. Coping has been conceptualized as context-specific behavior that includes voluntarily engaging or disengaging with the sources of stress (Compas, Jaser, Dunn, & Rodriguez, 2012). Voluntary coping strategies include Primary Control

Engagement Coping, Secondary Control Engagement Coping and Disengagement Coping. Primary Control Engagement Coping includes strategies to minimize the source of stress or minimize one's response to it, and also includes the use of problem solving in order to deal with stressors. For example, a question identifying use of Primary Control Engagement Coping in the form of problem solving is "I do something to try to fix the stressful parts of having CHD" (Compas et al., 2000). Ultimately, it is thought that Primary Control Engagement Coping may help account for differences in health behaviors because the way an individual copes may or may not allow him/her to utilize knowledge of future risks in order to engage in regular physical activity and eat a diet low in saturated fat. Furthermore, it is important to study the role of coping because coping is not a stable trait and individuals can be taught to implement strategies that lead to healthier ways of coping.

The first aim of the study was to (a) evaluate perceived risk for future health complications and the accuracy of risk knowledge among adolescents and young adults with CHD, as well as (b) determine the association between perceived risk, risk knowledge, and engagement in a low-fat diet and physical activity. It was hypothesized that greater risk knowledge would be associated with eating a lower-fat diet and being more physically active because individuals who have acquired more knowledge would also better appreciate the benefits of a healthy life style. The second aim was to examine whether Primary Control Engagement Coping moderates the relationship between risk knowledge and health behavior. It was predicted that risk knowledge would interact with Primary Control Engagement Coping to predict participation in health behavior such that those with greater knowledge who used more Primary Control Engagement Coping

would eat diets lower in saturated fat and engage in more physical activity. This is because they are actively trying to change the source of stress and so individuals with greater knowledge of future risks who do more Primary Control Engagement Coping will engage in better health behaviors in order to off-set future health complications.

Methods

Participants

A sample of 200 individuals with CHD were recruited from the adult and pediatric outpatient cardiology clinics at Nationwide Children's Hospital (52% females; 87% Caucasian). Fourteen individuals declined, resulting in a 93% recruitment rate. Ages ranged from 15-39 years ($M = 24.5 \pm 6.7$). Participants were stratified to represent three age groups with 29% adolescents (15-18 y.o.), 32% emerging adults (19-25 y.o.), and 39% young adults (26-39 y.o.). Diverse cardiac lesion severities were represented with 23% simple, 45% moderate, and 32% complex. Participants had to be able to read, write and speak English, and could not have a developmental disability or a genetic syndrome.

Procedure

Eligible participants were identified according to clinic rosters before their clinic appointment date, and they were contacted two to four weeks prior to their clinic appointment at NCH to notify them of their ability to participate in the study. They were asked to complete the surveys online prior to coming to clinic, but if that was not possible or if the individual was unable to be reached prior to their clinic appointment, they were approached during their appointment. The surveys required approximately one hour and 15 minutes to complete, and participants were compensated $50 for their time.

Measures

Participants completed a battery of questionnaires that included four measures used in this study:

The Congenital Heart Disease Assessment of Information Measure (CHD-AIM) (Jackson, Daniels, & Vannatta, 2012) is an 11-item measure that asks individuals to report information about their diagnosis and treatment history, expectations for and understanding of future health risks, and general knowledge about CHD. Generated scores include perceived risk , risk knowledge, and general knowledge. For the present study, the CHD AIM was used to measure perceived risk and risk knowledge. Participants were given a list of 6 items to choose from with each item representing a possible future health complication. The items were arrhythmia, heart failure, stroke, aortic aneurysm, hypertension and coronary artery disease. Perceived risk refers to the actual number of risks a participant endorsed regardless of whether the participant is actually at risk for developing the complications. Scores could range from 0 to 6. Risk knowledge specifically refers to the number of future health risks that the participant correctly identified given his/her personal diagnosis, as well as correctly identifying the symptoms of those conditions. For risk knowledge, a final score was given as a percent correct out of 100.

Godin Leisure-Time Exercise Questionnaire (GLTWQ) (Godin, Jobin, & Boullion, 1986),This measure was given to determine participant physical activity levels by measuring the intensity and frequency of physical activity within a typical week. Participants were asked to indicate the number of 15-minute intervals in which they engaged in strenuous, moderate and mild exercise. Strenuous activity included any time

the heart was beating rapidly, moderate was any activity that did not lead to exhaustion and that did not fall under mild exercise, and mild exercise included exercises that required minimal effort. Examples were listed for each of these categories to help participants more accurately determine in which category an activity belonged. Furthermore, the questionnaire asked participants to indicate how many times a week they engaged in a leisure-time activity that caused an increase in heart rate. The GLTWQ was scored by assigning a 9 to strenuous activities, 5 to moderate and a 3 to light. These numbers were multiplied by the number of times a week the participant reported participating in these categories and the three scores were added together. The composite score was used to measure a participant's physical activity and a higher number indicated more physical activity. A score of 24 or more units indicates an active lifestyle, while an individual with a score under 23 is considered to be insufficiently active (Godin, 2011).

Northwest Lipid Research Clinic Fat Intake Scale (FIS) (Retzlaff et al., 1997).This measure was used to assess self-reported saturated fat intake. The FIS includes 12 questions that ask participants to indicate which foods they commonly consume, given choices of foods that are the primary contributors of saturated fat in diet including cheese, snack foods, and desserts. Examples are given of specific foods that fall under each category. Each question has three or four responses to choose from, with each response containing increasingly more saturated fat than the previous response. Numeric point values are assigned in accordance to the level of saturated fat content such that consumption of higher saturated fat foods results in more points. The score is derived by summing the points of the 12 questions. A diet is considered low to moderate in

saturated fat if the score is equal to or less than 24. A score above 24 indicates a diet likely high in saturated fat.

Responses to Stress Questionnaire (RSQ) (Compas et al., 2000). The RSQ was initially created for pediatric cancer patients but was adapted to refer to stressors thought to be faced by individuals with CHD. Before use in this study, the adapted RSQ was tested on a small group of participants to see if the stressors were relevant. The RSQ starts with a series of questions about how stressful certain aspects of having CHD are for the participant, from being not at all stressful to very stressful. These include questions about paying for healthcare, uncertainty about the future, and the stress of having to communicate healthcare needs with family and friends.

Fifty-seven questions then follow, measuring voluntary and involuntary responses to those stressors. Three subscales represent voluntary coping strategies (Primary Control Engagement, Secondary Control Engagement, and Disengagement Coping) and two represent involuntary or automatic responses (Involuntary Engagement and Involuntary Disengagement). For this study, only voluntary coping strategies were examined, specifically Primary Control Engagement Coping. Primary Control Engagement Coping includes active strategies intended to directly change the source of stress (e.g., problem solving) or one's emotional reactions to the stressor (e.g., emotional expression and emotional modulation). The other voluntary coping strategies the RSQ measures are Secondary Control Engagement Coping, which includes cognitive restructuring, positive thinking, acceptance, and distraction, and Disengagement coping which involves denial, avoidance, and wishful thinking. Ratings given to items are summed within each subscale and divided by the measure total score to create proportion

scale scores. Therefore, an individual may predominantly use Primary Control Engagement Coping (65%), with the rest of their proportion score consisting of other forms of coping.

Medical Chart Review. A review of each participant's medical record was conducted to collect participant diagnosis, reparative history, and medications. This information was used to determine the participant's score for the risk knowledge variable.

Statistical Analysis Plan

To test Hypotheses 1a and 1b, Pearson's correlations examined the relationship between patient perceived risk, risk knowledge, and health behaviors, including engagement in physical activity and saturated fat intake (GLTWQ and FIS). To test Hypothesis 2, hierarchical multiple regression was used to test whether Primary Control Engagement Coping moderates the association of perceived risk or risk knowledge and health behaviors. This involved computation of interaction terms that are the products of the independent variables (perceived risk or risk knowledge and Primary Control Engagement Coping) to see if that term accounted for variance in health behaviors beyond the main effects of those predictors. Before computation of the interaction terms, the independent variables were centered by subtracting the mean score from all individual scores, generating a new mean of zero.

Results

Descriptive data for the measures are presented in Table 1. Results show that the mean number of conditions participants believed they were at risk for out of 6 possible conditions was 1.7 (SD = 1.5). The mean for risk knowledge was 51% (SD = 28%),

suggesting poor understanding of future health risks. The mean fat intake score of 30 (SD = 5.3) indicates that individuals in this study consume, on average, diets high in saturated fat. Furthermore, the mean score of 28.5 (SD = 22.9) on the GLTWQ suggests that participants on average are leading active lifestyles.

Pearson's correlations were used to determine the associations between risk knowledge, perceived risk, and health behaviors (saturated fat intake and physical activity). Correlations between measures can be found in Table 2. Participants who perceived themselves as having a greater number of future health risks (perceived risk) were more accurate in identifying future health risks and their symptoms (risk knowledge). Older participants were more accurate in identifying future risks, and greater risk knowledge was associated with less saturated fat intake. Physical activity was negatively correlated with risk knowledge and also negatively correlated with age, indicating that the more accurate individuals were in identifying future risks, the less physical activity they engaged in. Older participants engaged in less physical activity as well.

Results of the hierarchical multiple regression analysis testing coping as a moderator of the association between risk knowledge and saturated fat intake showed that Primary Control Engagement Coping did not interact with risk knowledge to predict saturated fat intake (Table 3) or physical activity (Table 4). However, results trended in the predicted direction (Table 3).

Discussion

The population of individuals surviving into adulthood with CHD in the United States is growing at a rate of 5% each year (Brickner, Hills, Lange, 2000). Consequently, there is

an increasing number of people who must manage and cope with a life-long illness that presents the possibility of future health complications. Previous research shows that individuals with CHD have a poor understanding of their condition and health requirements necessary to prevent these future complications. Until this study, however, there have been no other studies examining the relationship between patient future risk knowledge and engagement in health behaviors that mitigate future cardiac complications, or how coping moderates this relationship.

This study allowed for the examination of the relationship between risk knowledge and health behaviors in a large sample of individuals with CHD with a new, creative measure made specifically for CHD patients. Furthermore, the development of the RSQ measuring specific stressors associated to living with CHD allowed for identification of individual coping styles in relation to living with CHD.

Results showed that adolescent and adult survivors of CHD have a poor understanding of what conditions they are at risk for due to their cardiac condition. This is consistent with previous research showing that individuals have a poor understanding of other aspects of their disease, including diagnosis and need for follow-up care (Iversen, Vejlstrup, Sondergaard, Nielsen, 2007). While perceived risk and risk knowledge are associated with each other, only risk knowledge was predictive of eating a lower-fat diet. Therefore, patient education for improving risk knowledge may be beneficial for improving diet, thereby avoiding certain future health complications.

The negative correlation between risk knowledge and physical activity shows that individuals with better risk accuracy engage in less physical activity. This may indicate that even individuals with CHD who are aware of their future health risks may not know

the appropriate amount of physical activity in which to engage in order to avoid future health complications. As Sable et al. (2011) found, one barrier to engaging in the recommended amount of physical activity for individuals with CHD was fear of exercise being unsafe. In reality, only a few complex lesion types require physical activity restrictions and so improvements in patient education may lead to better understanding of how individuals with CHD can best benefit from engagement in physical activity (Sable, Foster, Uzark, et al., 2011).

The results of the multiple regression analyses testing Primary Control Engagement Coping as a moderator of the relationship between risk knowledge or perceived risk and health behaviors, while non-significant, trended in the predicted direction. Future studies should try to understand what role coping plays in the engagement of health behaviors with a measure that has been psychometrically validated in individuals with CHD. It could be that the adapted version of the RSQ for CHD individuals did not accurately identify participant use of Primary Control Engagement Coping.

Limitations in the study, including the use of self-report measures for health behaviors, could also account for the lack of significance in the results. Future studies should use objective measures of diet and physical activity to better understand the level of engagement in positive health behaviors among CHD survivors since studies have shown that individuals do not always respond truthfully on self-report measures in order to appear more socially desirable (Arnold and Feldman, 1981).

As the population of individuals with CHD in the United States continues to grow, it is becoming more important to identify ways of helping them mitigate future

health complications. This study found that people with CHD were only 51% accurate in identifying their own future health risks due to having CHD and so there is still room for improvement for individuals who could not correctly identify their future risks. While the negative correlation between risk knowledge and saturated fat intake indicates that individuals who know more about their future risks eat less saturated fat, the negative correlation between risk knowledge and physical activity indicates that perhaps these individuals do not understand the appropriate amount of physical activity in which they should engage. The fact that individuals with CHD are at risk for numerous future health complications, and since many of these complications may be prevented by engagement in positive health behaviors means that patient education with the goal of improving health behaviors can have major implications in the physical and mental quality of life for this underserved population.

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Table 1

Descriptive statistics of risk knowledge, perceived risk, and health behaviors

Variable	**N**	$\bar{x}$	**SD**	**Range**
Risk Knowledge	187	51%	28%	0 – 100%
Perceived Risk	199	1.7	1.5	0 – 6.0
Saturated Fat Intake	193	30.4	5.3	13.0 – 43.0
Physical Activity	168	28.5	23.0	0 – 78.0
Age	200	24.5	6.7	15.1-39.9

Table 2

Associations between age, risk knowledge, perceived risk, and health behaviors

Measure	**Age**	**Risk Knowledge**	**Perceived Risk**	**Diet (Sat. Fat Intake)**	**Phys. Activity**
Age	--	0.48*	0.31*	- 0.12	- 0.29*
Risk Knowledge	0.48*	--	0.59*	- 0.28*	- 0.21*
Perceived Risk	0.31*	0.59*	--	- 0.12	- 0.24*
Diet	- 0.12	- 0.28*	- 0.12	--	- 0.01
Phys. Activity	- 0.29*	- 0.21*	- 0.24*	- 0.01	--

*correlation is significant at the 0.01 level (2-tailed, DF = 166-198 due to missing data from some participants.)

Table 3

Hierarchical regression predicting dietary fat from perceived risk or risk knowledge and coping

Step	Predictors	Step 1 β	*p*	Step 2 β	*p*
1. $\Delta R^2 = .00$	Perceived Risk (PR)	-.12	.103	-.13	.078
	Primary Control Coping (PCC)	-.00	.959	.08	.919
2. $\Delta R^2 = .01$	Interaction (PR x PCC)			-.09	.203
1. $\Delta R^2 = .08$	Risk Knowledge	-.28	.000	-.26	.000
	Primary Control Coping (PCC)	.02	.807	.03	.641
2. $\Delta R^2 = .09$	Interaction (PR x PCC)			-.12	.091

Table 4

Hierarchical regression predicting physical activity from perceived risk or risk knowledge and coping

Step	Predictors	Step 1 β	*p*	Step 2 β	*p*
1. $\Delta R^2 = .05$	Perceived Risk (PR)	-.23	.003	-.24	.002
	Primary Control Coping (PCC)	.10	.188	.12	.130
2. $\Delta R^2 = .06$	Interaction (PR x PCC)			-.09	.236
1. $\Delta R^2 = .04$	Risk Knowledge	-.21	.009	-.19	.013
	Primary Control Coping (PCC)	.11	.178	.12	.145
2. $\Delta R^2 = .04$	Interaction (PR x PCC)			-.07	.417